Kentucky Coordinated Statement of Need
2009

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Contributors in this process included direct service providers, the HIV/AIDS prevention program coordinators, the state branches of STD, Tuberculosis, and Medicaid, Ryan White administrative staff, other public health agency representatives, the community planning group for HIV prevention and care, Ryan White Part B grantees, Part C clinics, the Part F AIDS Education Training Center, Part F dental reimbursement program providers, providers of substance abuse and mental health treatment, Veteran's Administration staff, Departments of Education staff, and correctional health providers. The success of this effort is due to the collaborators who pulled together to critically consider the best interests of individuals living with HIV/AIDS in Kentucky.

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I. Introduction

The Statewide Coordinated Statement of Need (SCSN) process is a means for the HIV/AIDS Branch to assess efficacy of HIV services in Kentucky and engage key stakeholders in a process of identifying unmet needs. The HIV/AIDS Branch of the Kentucky Department for Public Health initiated the Statewide Coordinated Statement of Need (SCSN) process with an initial process in 1999. Subsequent to this activity, the Branch conducted additional SCSN processes in 2003 and 2005 respectively.

The process for the SCSN in Kentucky has historically been a process in which stakeholders review a synthesis of assessments and make additional input. In the past, there were minimal efforts to engage individuals across programs in the process of analyzing original source documents. In previous SCSN activity, little emphasis was placed on attempting to begin a process of identifying possible interventions to address the unmet needs identified in the SCSN.

The attempt in 2009 is to enhance the previous processes by: 1) creating an opportunity for more thorough engagement of all stakeholders in the process, 2) making the needs assessment more comprehensive by integration of HIV prevention issues in the review, 3) carefully linking the findings of the 2009 SCSN with the State Comprehensive Plan, and 4). including strategies to address major needs/issues identified.

Per the SCSN Guidance, the stakeholder's principal task was the review and synthesis of existing needs assessment data. These materials include previous SCSN's and additional documents produced as part of prevention and care planning and efforts to identify and describe unmet needs of Kentuckians living with HIV/AIDS. These documents are identified in Section VI of this document, and summaries and descriptions of all the source documents are included.

The 2009 SCSN process was a collaborative effort among PLWHA, medical and support services providers, the State Departments of Education and Corrections, the State Tuberculosis, STD, Medicaid and HIV/AIDS Prevention programs, representative from all Kentucky Ryan White grantees, KHPAC [the prevention and care community planning and legislative advisory body], and a host of other HIV/AIDS stakeholders. Between August and December 2008, these participants assisted the HIV Care staff in formulating a complete and prioritized statement of need, which included a review of existing needs assessment data and developing strategies for addressing areas of concern. The SCSN process utilized several workgroups, conference calls, electronic reviews of materials, and a stakeholder meeting in Louisville, Kentucky. Detailed explanation of the process follows in Section II of this document.

The SCSN is divided into eight sections and a conclusion. The process for this update to the SCSN is described in Section II, and a thorough review of the epidemiology of HIV in the State is presented in Section III. This epi update includes AIDS data and describes the epidemic in the state by risk exposure, gender, race and geographic region. The HIV data that appears was reported since 2005 when HIV data began being collected. This HIV data complements the AIDS data by offering a more current snapshot of the epidemic in Kentucky.
This document proceeds to describe services in Kentucky to individuals at risk for and living with HIV in Section IV. As a follow-up, a description of the unmet need estimate and framework is provided in Section V. In subsequent sections, the summary of findings from working groups is presented in two sections. In the first, the unmet needs are identified and presented. The participants in the SCSN process assisted the Branch by engaging in a prioritization activity to determine those unmet needs which commanded the most importance. These are highlighted in the narrative of the SCSN. Following this, collaborators assisted the HIV/AIDS Branch by proposing possible solutions to these unmet needs. These are detailed in Section VIII of the document. Section IX articulates issues related to challenges and response strategies for the care and treatment system regarding provision of services to disenfranchised PLWHA.

II. Process for 2009 Update

The Kentucky HIV/AIDS Branch, under the coordination of the state Ryan White Part B Program Office, developed a plan in mid-2008 to conduct an update to the Kentucky SCSN. In preparation, the staff of the Ryan White Part B Program reviewed the HRSA SCSN guidance and the SCSN reports from the states of Florida and Michigan in an effort to identify best practices. Per HRSA guidance, attempts were made in the initial planning process to bring together all relevant stakeholders to collaboratively develop a process. These included HIV care providers, Branch staff, representatives from the Ryan White Parts C, D, and F grantees in the State and individuals living with HIV and AIDS.

Initial internal discussions led to the creation of a draft plan for conducting the SCSN and a shared agreement that the process might be aided by utilizing the skills of an external consultant. James Sacco, a consultant with some 20 years collaboration with HRSA-funded grantees, agreed to assist the Branch in the execution of the plan that was evolving. Using the information gathered from initial reviews of the SCSN guidance and sample SCSN reports, the Branch worked with the consultant to develop a template and action plan for the process of producing the 2009 Kentucky SCSN report.

The first steps after the initial planning process involved the consultant reviewing all relevant documents and previous needs assessments and creating a list of cross-cutting issues. From this process, the Branch created a structure by which volunteers from all the participating stakeholders could assist in a review of relevant material.

This large group process began with a call in July in which the Branch leadership and the consultant reviewed the guidance on SCSN, offered an overview of the task, and distributed the list of cross-cutting issues and template for smaller groups to form, review assessment materials and identify significant statewide care and prevention issues. Volunteers subsequently populated six working groups: Clinical Care, Care Coordination, Dental, Disenfranchised Populations, Prevention, and Collaborations. Each group had between 4 and 8 volunteers and each had a chair or co-chair to lead the process. A time line was developed and groups began the task of reviewing materials.

A follow-up call was conducted in August which included additional participants recruited by the Branch. These additional participants were updated about the process and assigned to one of the existing working groups. In September, an interim call was held with group co-chairs to invite additional input and gauge the progress of the working groups. This call advised a slight revision to the timetable and Branch staff and the consultant were able to offer technical guidance to the working groups. In mid-September, the groups subsequently submitted reports which included identified service gaps, unmet needs, and other relevant issues related to their assigned topics, as well as proposed strategies for addressing some of the issues.

Because of the critical importance of information regarding access to treatment and care, additional input from clinical care providers was sought. Working collaboratively with the Part C AETC local performance site at the University of Kentucky, additional response to issues related to unmet needs and challenges in the clinical care arena were identified by additional HIV clinicians. These unmet needs were incorporated into the existing document, which was merged with additional materials to become a draft SCSN. The consultant, working closely with Branch staff, compiled group reports into a draft of the 2009 Statewide Coordinated Statement of Need. This document was sent for review by all participants and a follow up call to refine content was held in September.

On October 16, 2008, the Branch convened a meeting of representatives from the Kentucky HIV/AIDS Planning and Advisory Council (KHPAC). This advisory/planning body oversees statewide community prevention and care planning activities, and provides legislative advisory as well. In addition, members of the SCSN working groups and affiliated stakeholders were invited to attend. Approximately 30 individuals attended this meeting and an additional six persons participated via conference call. This group represented Branch staff, persons living with HIV/AIDS, dental and medical care providers, HOPWA grantees, SAMSHA grantees, correctional facilities, local and county health departments, Ryan White Part B, C, D and F grantees and sub-grantees, AIDS service organizations, the Department of Corrections, the Department of Education, the state Communicable Disease branch, and HIV prevention staff from throughout the State.

The October meeting offered the Branch valuable feedback on the working draft of the SCSN and also advised them on priority problem areas. The group divided into smaller groups that were tasked with prioritizing unmet needs and offering a list of potential

solutions. The groups worked efficiently and very effectively and by the end of the day, the goals of the Branch were met. The work yielded very helpful feedback on the SCSN, a list of priority problems to be addressed, and a more thorough list of potential solutions to address the unmet needs in Kentucky.

Using this input, the Branch staff—working with the consultant—revised the 2009 SCSN to reflect the input from the October meeting. In addition, Branch surveillance and Ryan White Part B staff (with technical assistance from HRSA) began the internal processes of conducting an unmet need estimate and an assessment of service needs, gaps, and barriers to care for persons living with HIV/AIDS who are not in care.

The outcome of the SCSN leads directly to the process of creating a Statewide Strategic plan, and goals for 2009. Like many other jurisdictions, Kentucky is faced with a significant budget shortfall for FY 2009, and addressing the identified needs in the current economic environment will require resourcefulness beyond standard allocations and budgeting remedies. Specifically, Kentucky is developing strategies to partner with other entities to assist with addressing the concerns found in the 2008 SCSN.

The final 2009 SCSN will be submitted in January, 2009.

III. Epidemiological Profile of HIV/AIDS in Kentucky

HIV epidemiologic profile

As of December 31, 2007, there were 1,096 total HIV infections reported to the surveillance program since confidential name-based reporting started on January 1, 2005. Of these cases, 945 (86%) were still living; 211 (22%) concurrently diagnosed with AIDS during the same calendar month as the initial HIV diagnosis; and 734 (78%) with only HIV at the time of diagnosis. HIV (not-AIDS) data with confidential name-based reporting have been collected for three years. Therefore, trend analyses are not available. There were 354 and 403 new cases diagnosed with HIV disease in 2006 and 2007 respectively. The largest number of cumulative cases (n=556, 45%) were residing in the KIPDA Area Development District (ADD) which includes the city of Louisville. The second largest number of cases (n=259, 21%) were residents of the Bluegrass ADD at the time of diagnosis.

At the end 2006, there were a total of 693 HIV infections reported in Kentucky. Of these cases, 638 (92%) were living with HIV disease. The majority, were (519, 81%) White non-Hispanics had the largest proportion of living cases at 367 (57.5%), followed by Black non-Hispanics at 219 (34%) and Hispanics 35 (6%). The highest numbers of cases

living with HIV disease were among the 30-39 year age group (195, 31%), 40-49 year olds (181, 28%) and 20-29 year olds (161, 25%).

Men who have sex with men (MSM) comprised the largest category through which HIV was transmitted (335, 53%). Heterosexual relations with a person at risk for HIV also accounted for 124 (19%) of HIV infections. There was a significant volume of cases with an undetermined transmission category (27%), which could alter the distribution of cases and poses a barrier to timely and effective targeting of the individuals who are most vulnerable to HIV/AIDS through program planning and allocation of resources.

As of December 31, 2007, 1,096 HIV diagnoses had been reported to the surveillance program. Of these, 945 (86%) were living with the virus. The majority were males (758, 80%). The largest proportion of HIV infections was among those aged 30-39 (277, 29%) and 40-49 year olds (269, 29%). 526 (56%) of living cases in 2007 were among White non-Hispanics, and Black non-Hispanics (334 (35%). The distribution of risk factors remained the same in 2007, with majority of infections having been contracted through MSM exposure (452, 48%) and no risk factor indentified (231, 24%).

AIDS Epidemiologic profile

As of December 31, 2007, there were 4,730 total AIDS diagnoses reported in Kentucky to the Department for Public Health's HIV/AIDS surveillance program since 1982. Of these cases, 2,475 (52%) were still living. There were 216 and 237 new cases diagnosed with AIDS in 2006 and 2007 respectively. The KIPDA Area Development District (ADD) which includes the city of Louisville had the largest number of cumulative AIDS cases (2,209, 46%). The second largest number of cases (916, 19%) were residents of the Bluegrass ADD at the time of diagnosis.

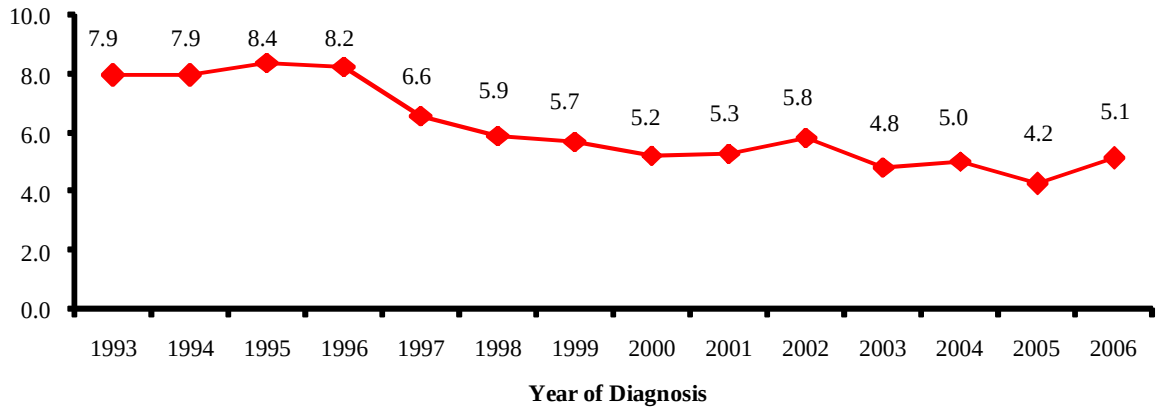
At the end 2006, there were a total of 4,529 AIDS diagnoses reported in Kentucky. Of these cases, 2,296 (51%) were living with AIDS with majority being male (1,890, 82%). White non-Hispanics had the largest proportion of living cases at 1,432 (62%), followed by Black non-Hispanics at 736 (32%) and Hispanics 107 (5%). The highest numbers of cases living with AIDS were among the 30-39 year age group (908, 40%), and 20-29 year olds (640, 28%). Men who have sex with men (MSM) comprised the largest category through which HIV was transmitted (1,215, 53%). Heterosexual relations with a person at risk for HIV accounted for 437 (19%) of HIV infections and Injected Drug Use (IDU) 310 (14%).

In 2007, there were 4,730 cumulative AIDS diagnoses reported to the surveillance program. A larger proportion of people were living with AIDS 2,475 (55%) in comparison with 2006. Of the living AIDS cases, 2,036 (82%) were male. There were no differences regarding race, with majority of living AIDS cases diagnosed among White non-Hispanics (1,522, 62%), and Black non-Hispanics (808, 33%). Those aged 30-39 (968, 39%) and 20-29 (681, 28%) represented the majority of living AIDS cases in

2007which was a similar trend to 2006 data. Majority of living AIDS cases identified their primary transmission category as MSM (1,289, 52%) and Heterosexual exposure (472, 19%).

As of June 30, 2008, there have been a total of 4,890 AIDS cases reported in Kentucky to the Department for Public Health's HIV/AIDS Surveillance Program since 1982. Of these reported cases, 2,915 are still presumed to be living. In 2007, there were 237 new AIDS cases diagnosed. The annual AIDS diagnosis rate among persons in Kentucky shows a trend by year of diagnosis (Figure 1). The annual AIDS diagnosis rate has remained fairly steady from 2000 to 2006, with slight fluctuations in 2002 and 2005.

Figure 1. Annual AIDS Diagnosis Rates Among Persons Diagnosed in Kentucky, 1993-2006*



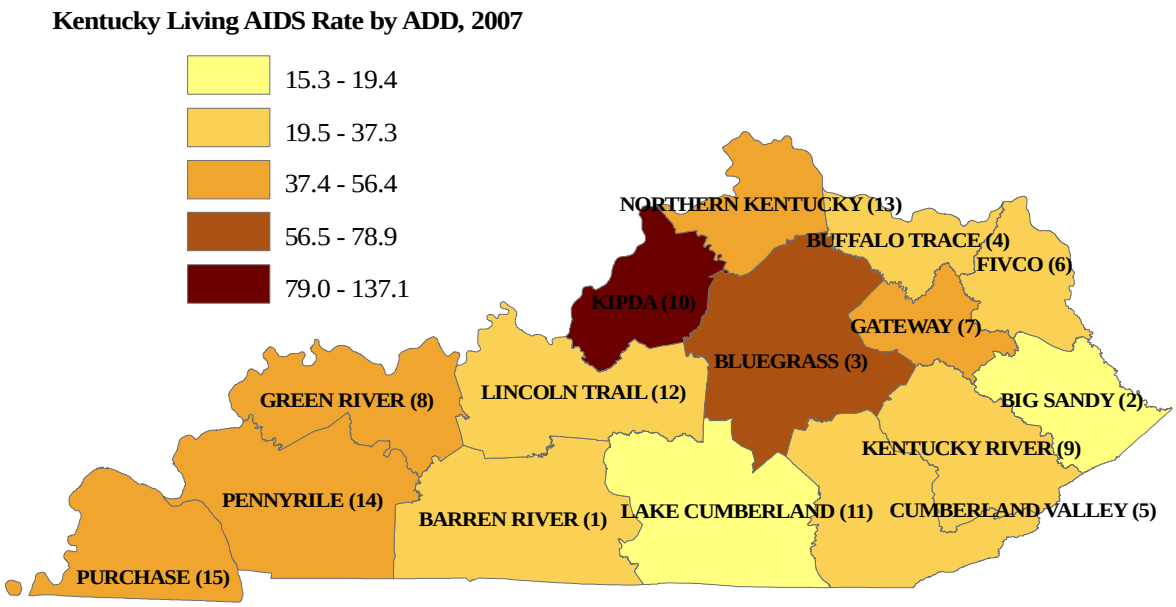


*Figure 2. Living AIDS Rates by Area Development District (ADD) of Diagnosis in Kentucky, 2007.

The rate of living AIDS cases is highest in the KIPDA area development district (ADD), which includes the city of Louisville. The rate of living AIDS cases is second highest in the Bluegrass ADD, which includes the city of Lexington. The rate of living AIDS cases is lowest in eastern Kentucky.

Figure 3. Percent of Reported Living AIDS Cases and Populations by Area Development District in Kentucky, 2007

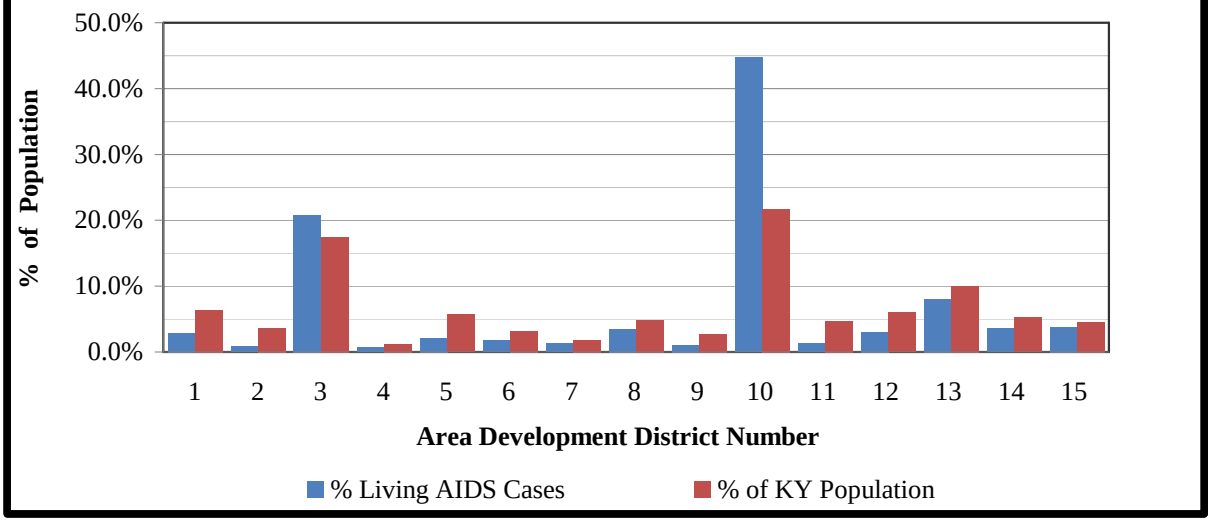
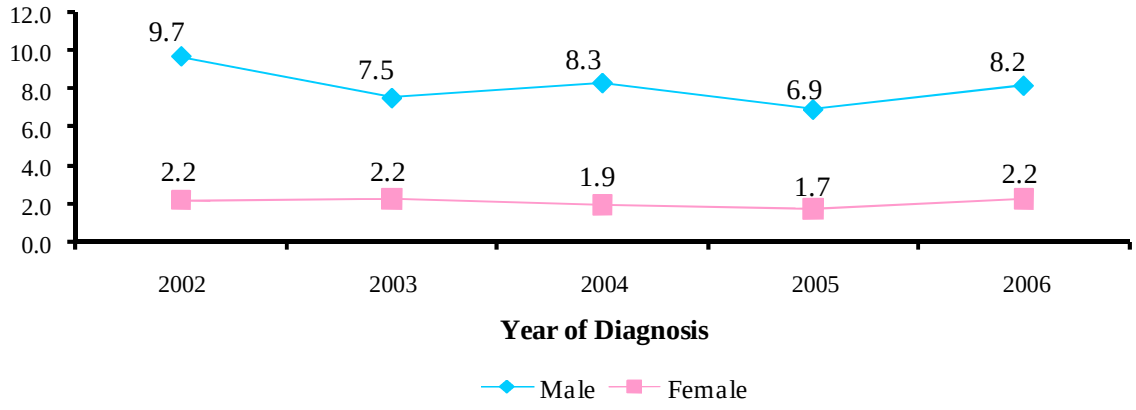


Figure 3 illustrates the disproportionate impact of AIDS on the Bluegrass ADD (3) and the KIPDA ADD (10), compared to the percent of people in the population. Although

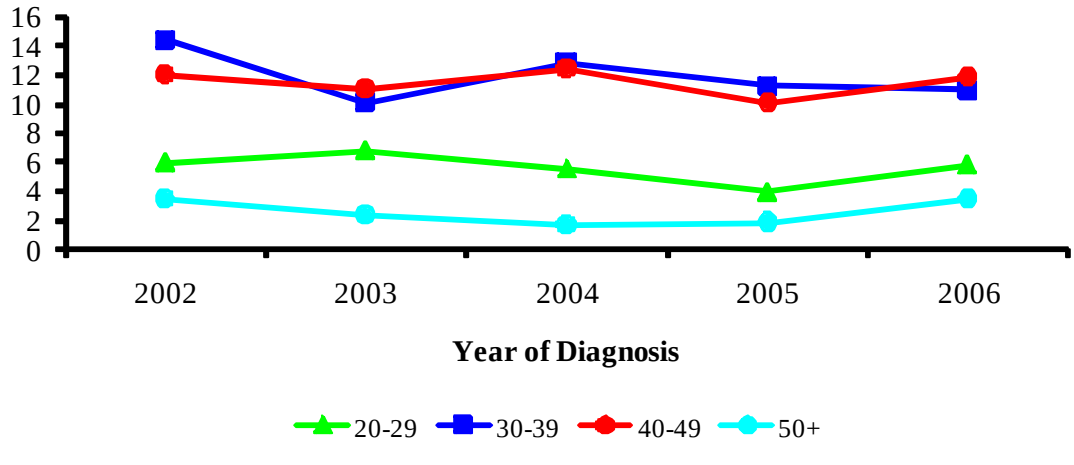
the KIPDA ADD comprises only 22% of Kentucky's residents, this area represents 45% of living AIDS cases diagnosed in Kentucky. The two ADDs with the disproportionate impact represent the largest population centers in the state.

Figure 4. Annual AIDS Diagnosis Rate Among Persons in Kentucky, by Sex, 2002-2006*



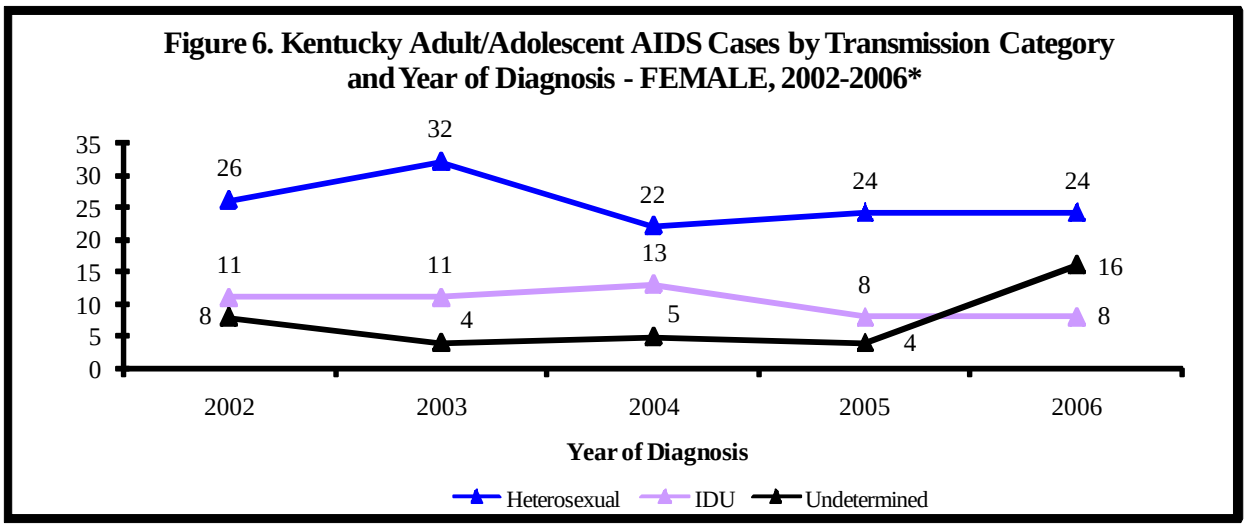
*Data for 2007 and 2008 are provisional due to reporting delays and are not used in trend analysis; all data are subject to change due to reporting delays. Males represent the majority (84%) of total AIDS cases reported in Kentucky through June 30, 2008. On average from 2002 to 2006, the AIDS diagnosis rate among males has been approximately four times higher than for females (Figure 5). The AIDS diagnosis rate among males has fluctuated from 2002 to 2006 while the female AIDS diagnosis rate has remained fairly steady from 2002 to 2006, with a slight decrease seen in 2004 and 2005.

Figure 5. Kentucky AIDS Diagnosis Rates* by Age and Year of Diagnosis, 2002-2006**

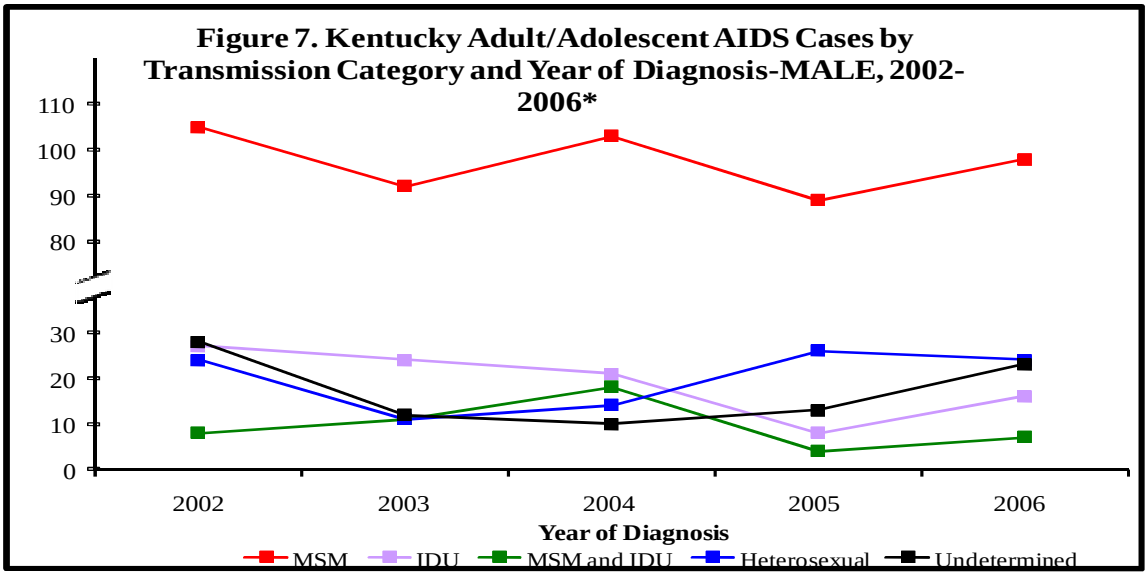


*Due to the small numbers of AIDS cases reported, rates are not presented for age groups 0-12 and 13-19 years old.
**Data for 2007 and 2008 are provisional due to reporting delays and are not used in trend analysis; all data are subject to change due to reporting delays.

Cumulatively through June 30, 2008, the largest percentage of AIDS cases were diagnosed in their 30's (42%), followed by those in their 40's (27%). The AIDS diagnosis rate has been highest among those in their 30's and 40's from 2002 to 2006 (Figure 5). There was a slight increase in the diagnosis rates for all age categories from 2005 to 2006, except among those 30 to 39 years of age.



* Data for 2007 and 2008 are provisional due to reporting delays and are not used in trend analysis; data are subject to change due to reporting delays.

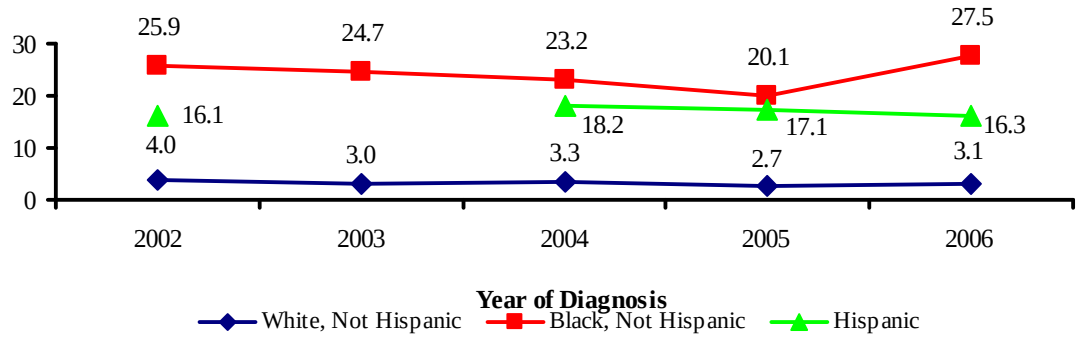


*Data for 2007 and 2008 are provisional due to reporting delays and are not used in trend analysis; data are subject to change due to reporting delays.

Figure 6 and Figure 7 show female and male Kentucky adult/adolescent AIDS cases by

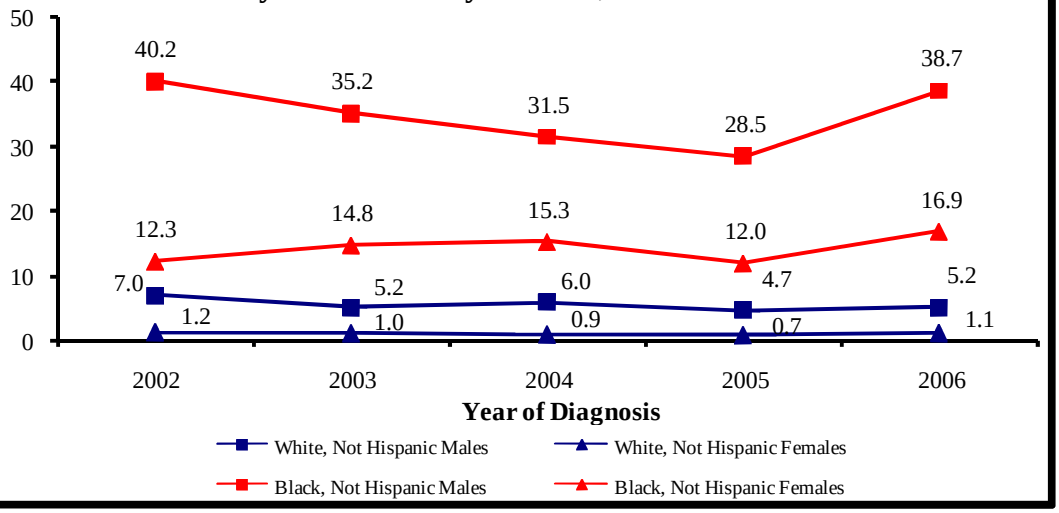
transmission category and year of diagnosis. The number of cases among females reporting heterosexual contact as the mode of transmission decreased from 2003 to 2004, and remained fairly steady from 2004 to 2006 (Figure 6). Also, the number of female cases reporting IDU as their primary mode of transmission decreased from 2004 to 2005. In Figure 7 for adult/adolescent males, please note the break in the y-axis for the number of cases diagnosed. Among males, MSM's account for the largest number of cases diagnosed each year from 2002 to 2006. The number of males reporting IDU as their primary mode of transmission decreased from 2002 to 2005, and then increased in 2006. The number of cases among males attributed to heterosexual contact increased from 2003 to 2005. Among both females and males the number of cases with an undetermined transmission category increased in 2006.

Figure 8. Kentucky AIDS Diagnosis Rates by Race/Ethnicity and Year of Diagnosis, 2002-2006*



*Data in 2007 and 2008 are provisional due to reporting delays and are not used in trend analysis. The diagnosis rate for Hispanics in 2003 is not presented because the number of cases diagnosed was less than 10.

Figure 9. Kentucky AIDS Diagnosis Rates by Race/Ethnicity and Sex, 2002-2006*[a]



*Data in 2007 and 2008 are provisional due to reporting delays and are not used in trend analysis.
[a] Rates for Hispanic cases by sex are not presented due to the small number of cases reported.

On average from 2002-2006, the AIDS diagnosis rate for blacks was approximately eight times higher than for whites, and five times higher for Hispanics than for whites in Kentucky (Figure 8). The diagnosis rate among black males has steadily decreased between 2002 and 2005 (Figure 9). The diagnosis rate among both black males and females increased from 2005 to 2006. This trend will continue to be monitored. The diagnosis rates among white males and females have remained fairly steady from 2002 to 2006 (Figure 9).

HIV Diagnoses

Between 2005 and June 30, 2008 there have been a total of 1,234 HIV infections reported in Kentucky (Table 1). Of these cases, 25% were concurrently diagnosed with AIDS during the same calendar month as the initial HIV diagnosis. The number of new HIV infections diagnosed between 2005 and 2007 and the proportion of concurrent diagnoses has remained fairly steady.

Table 1. Kentucky HIV Diagnoses, 2005-2008*

	Total HIV Diagnoses	Without AIDS		Concurrent with AIDS Diagnosis	
Year of Diagnosis	**N**	**N**	**%**	**N**	**%**
2005	339	256	76%	83	24%
2006	354	267	75%	87	25%
2007	403	307	76%	96	24%
2008*	138	101	73%	37	27%
Total	**1234**	**931**	**75%**	**303**	**25%**

*Data reported through June 30, 2008

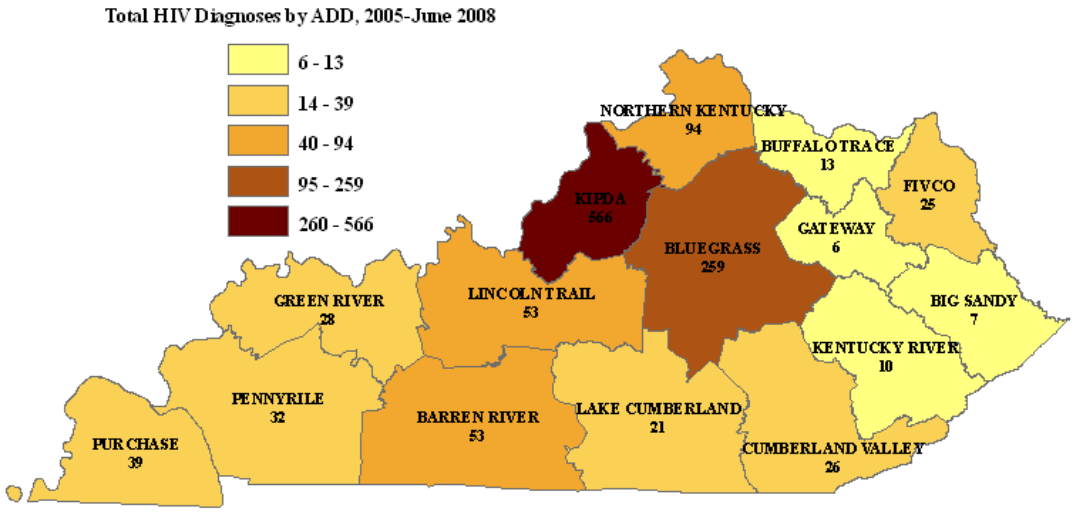


Figure 10 examines the total number of HIV infections diagnosed between 2005 and June 30, 2008 by ADD. The labels on the map represent the total number of HIV infections, regardless of disease progression status in each ADD. The largest number of cases (n=556, 45%) diagnosed in this period were residing in the KIPDA ADD, which includes the city of Louisville. The second largest number of cases (n=259, 21%) were residents of the Bluegrass ADD at the time of diagnosis. The smallest number of HIV infections diagnosed and reported during this period occurred in the ADD's located in eastern

Figure 11. Percent of HIV Infections Reporting Concurrent Diagnoses with AIDS by Area Development District (ADD) of Residence at Time of Diagnosis, 2005-June 2008

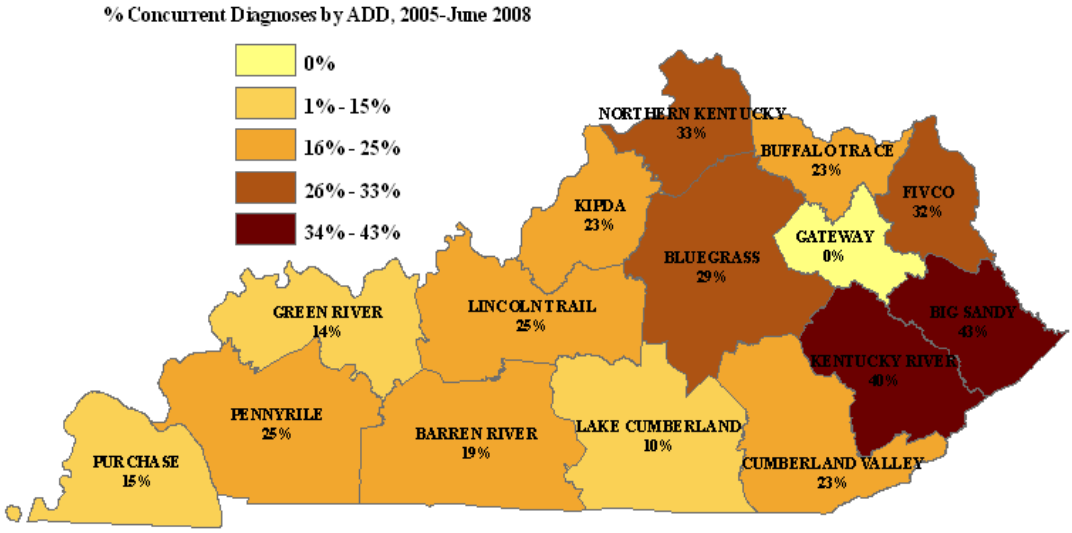
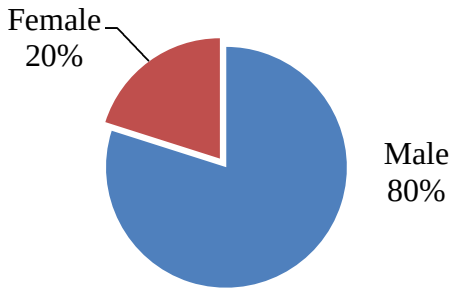


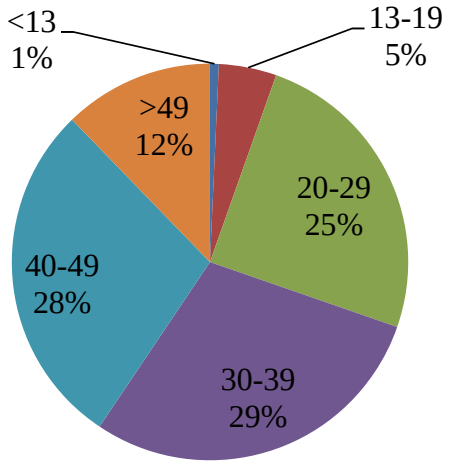
Figure 11 examines the variation by ADD in the proportion of cases within each ADD diagnosed concurrently with HIV and AIDS from 2005 to June 30, 2008. The proportion of HIV infections diagnosed concurrently with AIDS ranged from 0% to 43% among the ADDs. The greatest proportion of HIV infections diagnosed concurrently with AIDS (43%) occurred in the Big Sandy ADD in eastern Kentucky. However, there were only a total of seven HIV infections diagnosed in this ADD. The ADDs in northern Kentucky also had comparatively higher percentages of concurrent diagnoses.

Figure 12. Percentage of Kentucky HIV Diagnoses by Sex, 2005-June2008



Between 2005 and June 2008, 80% of all HIV diagnoses were reported among males. There were no differences in the distribution by sex between HIV cases diagnosed without AIDS, and cases concurrently diagnosed with HIV and AIDS in the same calendar month.

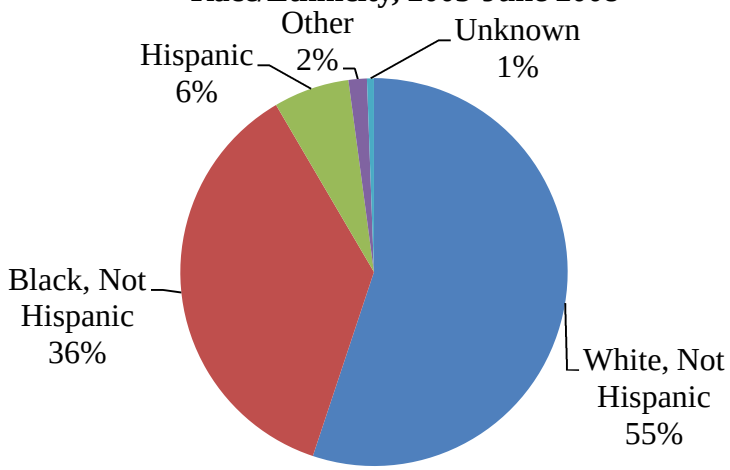
Figure 13. Percentage of Kentucky HIV Diagnoses by Age at Diagnosis, 2005-June 2008



Between 2005 and June 2008, 29% of new HIV diagnoses were reported among those 30-39 years of age (Figure 13). Eight-two percent of all HIV infections diagnosed in this time period were among individuals 20-49 years of age. There were differences in the distribution of age at diagnosis between HIV cases diagnosed without AIDS and cases

concurrently diagnosed with HIV and AIDS in the same calendar month. Among individuals diagnosed with HIV without AIDS, 25% of all cases were diagnosed among those 40-49 years of age. In comparison, individuals diagnosed between 40-49 years of age represented 38% of all HIV cases concurrently diagnosed with AIDS. In contrast, individuals diagnosed between 20-29 years of age represented 28% of HIV without AIDS diagnoses, but only represented 14$ of all cases concurrently diagnosed with AIDS.

Figure 14. Percentage of Kentucky HIV Diagnoses by Race/Ethnicity, 2005-June 2008



Whites represented 55% of all diagnosed HIV infections from 2005 to June 2008 (Figure 14). Blacks and Hispanics are disproportionately impacted by HIV. Although Blacks and Hispanics comprise only 7% and 1% of Kentucky's general population, respectively, based on 2000 U.S. Census data, they represent 36% and 6% of all new HIV diagnoses from 2005-2008. Hispanics made up a larger proportion (11%) of concurrently diagnosed cases than their proportion (5%) among individuals diagnosed with HIV without AIDS. This data suggests that Hispanics are being diagnosed and reported at a later stage than other race/ethnicity categories.

Figure 15. Percentage of Kentucky HIV Diagnoses by Transmission Category-Adult/Adolescent Males, 2005-June 2008

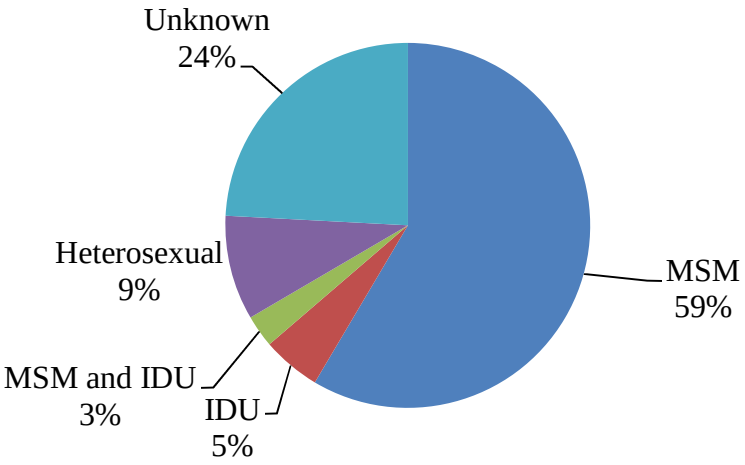


Figure 15 illustrates the distribution of HIV diagnoses from 2005 to June 2008 by transmission category among adult/adolescent males. The majority of HIV diagnoses within this time period have been attributed to men who have sex with men (59%). There are a large percentage of cases where the transmission category is unknown (24%). Cases with unknown transmission category information have not been proportionately re-distributed. The large percentage of missing cases makes it difficult to interpret this data.

Figure 16. Percentage of Kentucky HIV Diagnoses by Transmission Category-Adult/Adolescent Females, 2005-June 2008

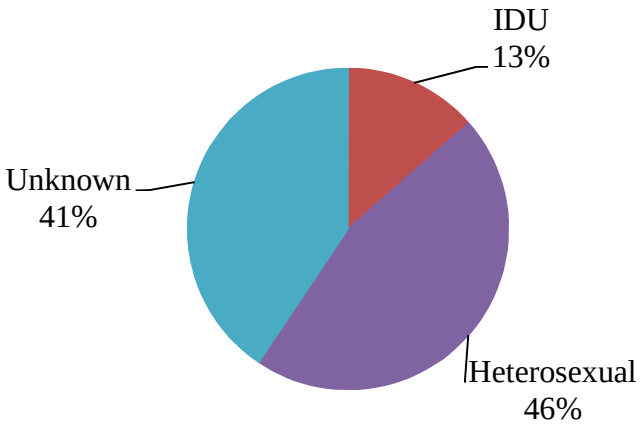


Figure 16 illustrates the distribution of HIV diagnoses from 2005 to June 2008 by transmission category among adult/adolescent females. The majority of HIV diagnoses within this time period have been attributed to heterosexual contact (46%). There are a

large percentage of cases where the transmission category is unknown (41%). Cases with unknown transmission category information have not been proportionately re-distributed.

IV. HIV Services in Kentucky

Kentucky Health Insurance Continuation Program

The Kentucky Health Insurance Continuation Program (KHICP) is a direct service component of the Kentucky Care Coordinator Program (KHCCP). This program provides payments for the continuation of health insurance benefits for eligible individuals at risk of losing their employment-related or private-pay insurance due to HIV disease. KHICP is largely federally-funded, and is the payor of last resort program for participants. KHICP assistance is not guaranteed.

In addition, the KHICP cannot make payments directly to participating clients. Six (6) regional contractors of the Care Coordinator Program regionally assist clients with insurance related matters, including payments for insurance premiums. KHICP services may differ among Care Coordinator regions depending on the funding and service priorities.

Kentucky AIDS Drug Assistance Program (KADAP)

The Kentucky AIDS Drug Assistance Program (KADAP) was created in 1990 as a result of the Ryan White CARE Act. KADAP is a state-administered program that provides HIV/AIDS medications and medications for the treatment of opportunistic infections to low-income HIV+ Kentuckians.

KADAP contracts with the University of Kentucky (Kentucky Clinic Pharmacy), as the sole provider of medications for KADAP clients. Eligible clients can receive KADAP formulary medications via mail order or walk-in pharmacy services.

Participants access KADAP services through the Kentucky HIV/AIDS Care Coordinator Program (KHCCP). Care Coordinators regularly coordinate their work schedules to be present on-site at Part C medical treatment clinics in order to assist potential clients with applications for KADAP and emergency medications. Care Coordinators from the Northern Kentucky region do not work on-site at a Part C clinic. This service area borders Cincinnati Ohio, and coordinates with the Part C clinic at the University of Cincinnati to facilitate prompt access to medications. In addition, each region has established relationships with private infectious disease medical providers in their respective areas to provide linkage to care.

Case Management/Care Coordination

It is mandatory that all recipients of Direct Service in Kentucky receive case management services through the Kentucky Care Coordination Program (KHCCP). Each Part B Care Coordination office provides case management services to all clients. It is through this relationship that the progress and administration of actual client care is monitored for outcomes and compliance issues.

In tandem with their Care Coordinator, each client assumes the responsibility, to the extent possible, of managing his/her own Individualized Care Plan (ICP). The ICP may include a variety if medical, support, mental health, substance abuse or other services referrals. Clients assist directly in the development of these plans, and both Care Coordinator and client are expected to comply with the ICP.
Care Coordination is provided in six regional sites. These regional locations and brief descriptions of their service activities are outlined below:

1. Bluegrass Care Clinic/BCC (Central and Eastern Region, Lexington, KY)

This agency operates a comprehensive HIV care services providing Ryan White Part B, Part C (medical treatment), mental health, substance abuse and HIV prevention services. This model allows clients to receive case management and medical care on the same day at one facility, minimizing travel and other expenses. BCC is a clinic on the campus of the University of Kentucky Hospital. This proximity expedites client access to medical subspecialty clinics, such as ophthalmology or renal services.

BCC coordinates with the Lexington Fayette County Health Department to provide housing services through the Housing Opportunities for Persons With AIDS (HOPWA) grant. Other linkages include meals-on-wheels, Comprehensive Care, other private infectious disease physicians, and oral health providers.

To ensure the provision of medical services to the underserved region of North Eastern Kentucky, BCC has partnered with Dr. Cecelia Gaynor (a private infectious disease physician) for client care. BCC also refers clients to the Portsmouth, Ohio City Health Department, which provides treatment for infectious disease patients.

2. Cumberland Valley District Health Department / CVDHD (Eastern Region, London, KY)

This agency receives Part B funding to provide medical care services to clients in Eastern Kentucky. In addition, CVDHD maintains a Memorandum of Agreement with the BCC to provide onsite medical case management for CVDHD Direct Services clients in the absence of a CVDHD Care Coordinator

CVDHD receives HOPWA funding for the eastern part of Kentucky. HOPWA funding subsidizes the costs associated with securing safe and affordable housing for clients.

In addition to the care and housing services described above, prevention services are also available through collaborations with the Lexington Fayette County Health Department and Volunteers of America, in Lexington, Kentucky.

3. Heartland Cares, Inc. (Western Region, Paducah, KY)

Heartland Cares receives Part B funding to provide direct services and a separate grant for medical treatment (Part C). At this location, clients can receive case management and medical care on the same day at one facility, minimizing travel and other program expenses.

Due to the remote location of this agency; Heartland Cares has developed a referral network of oral health providers.

This agency also receives federal grant funding for HOPWA for the western region of Kentucky. The HOPWA grant subsidizes the costs associated with securing safe and affordable housing for clients.

Heartland Cares receives separate funding from the State to provide HIV prevention initiatives, and linkages are in place to provide a broad spectrum of HIV prevention services, including risk reduction.

Collaborations have been established with the regional Comprehensive Care system in the area. The Comprehensive Care system is comprised of facilities able to treat physical and mental health conditions, including substance abuse.

4. Matthew 25 AIDS Services, Inc. (Western and South Central Region, Henderson, KY)

Matthew 25 receives Part B funding for direct services, and a separate grant for medical treatment. At this location, clients can receive case management and medical care on the same day at one facility, minimizing travel and other program expenses. This agency has an established referral network, with linkages to private mental health providers in the area.

The agency refers many clients to the regional Comprehensive Care system. To accommodate client needs, this agency has partnered with the Daviess County Health Department. In this partnership, Matthew 25 has been allotted meeting space, at the health department, allowing for weekly meetings between Matthew 25 Care Coordinators and area clients. At the health department, clients can receive case management and medical care on the same day at one facility, minimizing travel and other program expenses.

This agency utilizes the University of Louisville's Elizabethtown Part F program (oral health services) as a referral source. In addition, there is a Care Coordinator at the Elizabethtown office available to clients at this location.

Matthew 25 directly-funded for HIV prevention through a contract with the Centers for Disease Control and Prevention (CDC).

5. Northern Kentucky Independent District Health Department (Northern Region, Ft. Mitchell, KY)

Because this agency is located in the far northern part of Kentucky, many client medical referrals are made to the Part C clinic at the University of Cincinnati Hospital in nearby Cincinnati, Ohio.

The agency also receives a small amount of federal grant funding for HOPWA to subsidize the costs associated with securing safe and affordable housing for clients.

A Memorandum of Agreement currently exists between this health department and the Droege House- a residential facility in Dayton, Ohio specializing in substance abuse issues. The facility accommodates HIV positive individuals within their substance abuse treatment program.

This agency refers many clients to the regional Comprehensive Care system. When indicated, clients can be referred to onsite HIV prevention services. In such cases, a prevention specialist schedules an appointment with the client.

6. Volunteers of America, VOA (North Central Region, Louisville, KY)

VOA has a standing Memorandum of Agreement with the University of Louisville "WINGS" (Part C) medical treatment clinic, and routinely refers clients to that location for treatment. Also, VOA has a Care Coordinator stationed at the Part C clinic– to provide clients with case management from VOA and medical care on the same day at one facility, minimizing travel and other program expenses.

VOA is part of the AIDS Services Organization (ASO) in Louisville. This organization consists of all of the HIV/AIDS service organizations in the Louisville/Jefferson County area. The ASO is in charge of the yearly "Louisville AIDS Walk." The money raised is then distributed among the ASO partners to assist HIV infected individuals.

VOA has an agreement with the Hoosier Clinic in Jeffersonville, Indiana to provide Ryan White Part B funding to the clinic, in order to subsidize medical treatment for referred clients.

Collaborations with providers such as Seven Counties, VOA substance abuse, Louisville/Metro Health Department and House of Ruth have been established to provide a continuum of care and supportive services. This agency refers clients to the University Of Louisville School Of Dentistry (Part F) for oral health needs.

VOA receives separate funding from the State to provide HIV prevention initiatives, and linkages are in place to provide a broad spectrum of HIV prevention services, including risk reduction.

Grant Administration

Each component of the Kentucky Direct Services program has a designated administrator within the state HIV/AIDS Branch. Each program component is administered from the Kentucky Cabinet for Health and Family Services' HIV/AIDS Branch.

V. Assessment of Unmet Need

KENTUCKY UNMET NEED ESTIMATE AND ASSESSMENT

: Unmet need Framework for the year 2007: Ryan White Part B Program

Population Sizes		**Value**		**Data Source(s)**
Row A	PLWA[1]	2,543		HARS
Row B	PLWH[2], non-AIDS	1,603		HARS
Row C	Total PLWH/A[3]	4,146		HARS
	Care Patterns	**Value**		**Data Source(s)**
Row D	Number of PLWA who received HIV primary medical care during the 12-month period January 1, 2007-December 31, 2007	1,706		Laboratory database, Ryan White Part B Program. Number of persons living with HIV who had a Elisa, Western blot, PCR, HIV antigen or HIV culture, CD4+ assays HIV viral load assays, a positive serologic test result for HIV infection or care through the Ryan White Part B Program in the 12 month period.
Row E	Number of PLWH/non-AIDS who received the specified HIV primary medical care during the 12-month period January 1, 2007 - December 31, 2007	1,129		Laboratory database, Ryan White Part B Program. Number of persons living with HIV who had a Elisa, Western blot, PCR, HIV antigen or HIV culture, CD4+ assays HIV viral load assays, a positive serologic test result for HIV infection or care through the Ryan White Part B Program in the 12 month period.
Row F	Total number of HIV+ who received the specified HIV primary medical care during the 12-month period January 1, 2007 - December 31, 2007	2,835		Laboratory database, Ryan White Part B Program. Number of persons living with HIV who had a Elisa, Western blot, PCR, HIV antigen or HIV culture, CD4+ assays HIV viral load assays, a

				positive serologic test result for HIV infection or care through the Ryan White Part B Program in the 12 month period.
	Calculated Results	**Value**	**Percent**	**Calculation**
Row G	Number of PLWA who did not receive the specified HIV primary medical care	837	33%	Value = A - D Percent = G/A
Row H	Number of PLWH/non-AIDS who did not receive the specified HIV primary medical care	474	30%	Value: B - E Percent: H/B
Row I	Total HIV+ not receiving the specified HIV primary medical care (quantified estimate of unmet need)	1,311	32%	Value: G + H Percent: I/C

[1] People living with AIDS
[2] People living with HIV- not AIDS
[3] People living with HIV and/or AIDS

Data are current as of June 30, 2008, therefore not similar to the data presented in the epidemiologic profile. These tables compare persons living with HIV and/or AIDS with met need to those with unmet need through laboratory data and Ryan White Part B Program data.

Narrative Description
Data Sources and Estimation Methods Used:

The following methodology was used in order to estimate unmet need for HIV-related primary care in Kentucky.
First, three databases were selected:

- *The HIV/AIDS Reporting System* (HARS). HARS is the surveillance database that contains information on reported cases of HIV/AIDS in Kentucky. Cases entered in HARS were either diagnosed in the state of Kentucky or are currently living in the state since being diagnosed elsewhere. HARS contains the population-based data needed to determine the population size of HIV-infected persons.

- *Laboratory Database*. Mandatory laboratory reporting in Kentucky for all HIV positive tests include Elisa, Western blot, PCR, HIV antigen or HIV culture, CD4+ (assays including absolute CD4+ cells and CD4%), HIV viral load assays and a positive serologic test result for HIV infection. These laboratory results are contained in an ACCESS database maintained by the HIV Surveillance program.

- The Ryan White Part B Program datasets comprise of Kentucky AIDS Drug Assistance Program (KADAP) data (which contains utilization data for clients who receive one or more pharmaceutical services in the Program) and care coordinator data that tracks demographics and client utilization of the core and supportive services through the program.

Second, "care" was defined as having a laboratory result Elisa, Western blot, PCR, HIV antigen or HIV culture, CD4+ assays HIV viral load assays and/or a positive serologic test result for HIV infection during the 12 month time period (January 1, 2007 through December 31, 2007) among patients in HARS. Use of anti-retroviral therapy was not included in the definition of care because HIV Surveillance does not collect this information routinely. However, it is believed that the vast majority of patients on medication regularly have CD4 and viral load tests to measure compliance and effectiveness. There are few, if any, patients in care who are missed using laboratory data only.

Third, laboratory data were used to determine each patient's most recent Elisa, Western blot, PCR, HIV antigen or HIV culture, CD4+ assays, HIV viral load assays, and/or a positive serologic test result and date. These laboratory results were then joined to surveillance data in HARS including all living cases diagnosed with HIV/ AIDS in Kentucky. Persons diagnosed after December 31, 2007 were excluded from analysis to eliminate the possibility of including those who were recently diagnosed and had not yet established care. Unmet need was then calculated by determining the number of persons in HARS who were diagnosed prior to December 31, 2007, were living in Kentucky and had not received a laboratory result between January 1, 2007 and December 31, 2007.

Fourth, Ryan White Part B Program Data were used to further determine persons in HARS who had no record of laboratory tests in the laboratory database but who received HIV related primary care through the Part Bprogram. All HARS cases with no record in the laboratory database were matched against the program's data to confirm whether they had received care in the mentioned period.

Limitations:
While the combination of surveillance, laboratory and Ryan White Part B data offers an ideal way to measure unmet need, there are some limitations to the data that should be noted. The current system of recording cases into HARS has a limited way of identifying those who are being served in other states. Kentucky is bordered by seven states. It is common that treatment is sought in the nearest medical facility, which may be in a neighboring state. Unless the labs are done by a reference laboratory, there is no way to ensure that all labs being performed in private institutions are being reported to Kentucky HIV Surveillance. There inevitably is room for error in the laboratory reporting system; however, statistical quality checks are in place to ensure the quality of those data.

Although the Framework requests the number of persons who are aware of their status, HIV/AIDS surveillance is not able to capture HIV status awareness. Thus, the estimates in the Framework include all persons reported to surveillance and living in Kentucky, whether aware of their status or not. Also, not all diagnosed cases are reported to the HIV surveillance program; reporting delays and non-reporting of cases cause a gap in the numbers quoted here. In addition, in and out migrations were unaccounted for due to the application's (HARS) inability to effectively track people's physical addresses over time. This may slightly adjust the numbers of those falling under the unmet need category due to the mobility of persons receiving care in and out of the state of Kentucky. The numbers are lower than the data shown in the Epidemiologic profile due to different HIV/AIDS diagnosis date restrictions (only people diagnosed with HIV disease by December 31, 2007), and the recently completed death matching with the state death records.
We are currently matching those not in care identified through the laboratory database and the Ryan White Part B Program, with Medicaid data and hope to have an adjusted unmet need estimate for the comprehensive plan.

Assessment of Unmet Need: Analysis of Those Not in Care

The Unmet Need Framework shows that for the time period January 1, 2007- December 31, 2007 there were an estimated 1,603 persons living with HIV and 2,543 persons living with AIDS for a total of 4,146. There were 2,835 people estimated to have been in care during the year 2007 with 1,129 having HIV non-AIDS and 1,706 having AIDS. There were 1,311 (32%) people living with HIV and/or AIDS estimated to be out of care. Of these, 837 (33%) were living with AIDS and 474 (30%) were living with HIV not-AIDS.

Of the 1,311 persons with unmet need, 1,082 (83%) were male and 229 (17%) were female. The majority of persons with HIV and/or AIDS, with unmet need were white, non-Hispanic 727 (55%), followed by black, non-Hispanic 487 (37%). Among Hispanics, 77 (6%) had unmet need in the year 2007. Persons with unmet need were more likely to live in the KIPDA ADD which includes the city of Louisville 585 (45%), Bluegrass ADD which includes the city of Lexington 246 (19%) and Northern Kentucky ADD 165 (13%). Additionally, young adults and middle aged people at the time of HIV and/or AIDS diagnoses had higher rates of unmet need in comparison to other age groups: [491 (37%) among 30-39 year olds; 409 (31%) among 20-29 year olds; and 276 (21%) among those 40-49 years old]. Lastly, the proportion of unmet need was highest among persons reported in these primary transmission categories: MSM (Men who have Sex with Men) 649 (50%); Heterosexual 222 (17%); IDU (Injection Drug Use) 177 (14%); and undetermined modes of HIV transmission 178 (14%).

ADD means Area Development District. In Kentucky, there are fifteen. Conceptually, they were formed by local elected officials and citizens in the

Commonwealth to find collaborative means to deal with problems that beset their communities. For more information about ADDs, visit http://kycadd.org/index.html

VI. Findings from Needs Assessments and Related Documents

A. 1999 Statewide Coordinated Statement of Need

The 1999 SCSN focused on the unmet needs in Kentucky and updated the 1996 SCSN. The document details in depth challenges the State faced in addressing the medication needs of individuals living with HIV and challenges of effective, affordable housing solutions for Kentuckians living with HIV who were homeless or marginally housed.

A major structural challenge identified was the need for promotion of HIV Branch activities and need for public information about HIV. Concurrent with this, a need for education of all health care workers was emphasized. Linkages between substance abuse facilities and HIV care settings were also identified as a significant gap.

Prevention challenges identified included preventing perinatal transmission by enhancing commitment of obstetricians to HIV testing. In addition, concerns were raised about addressing needs of incarcerated populations for HIV prevention and linking HIV-positive inmates to care.

B. 2002 Kentucky Needs Assessment

This document centered on the findings from interviews with almost 300 clients enrolled in care in Title II (Part C) clinics. Difficulties identified included challenges affording medication, need for outreach to migrant workers, challenges of receiving care far from home (particularly in rural areas), and rates of unprotected sex after diagnosis.

Strengths identified included high levels of satisfaction with the services of care coordinators and their primary HIV care provider.

C. 2003 Statewide Coordinated Statement of Need

This document focused on the geographic characteristics, service disparities, and significant issues in Kentucky demographics. The data source for much of this document was a series of focus groups conducted throughout the state. The economic differences between Northern Kentucky and the rest of the State were noted, and the ways in which care happens often in neighboring Cincinnati, Ohio and outside the public health sector. Limited resources resulted in a strain on the KADAP program and on the care coordinators who provided this service.

In addition, this document clearly articulated the challenges between rural and urban Kentucky regarding a series of issues. The burden related to large numbers of clients per service provider was shown to be higher in urban areas, but the strain on resources was more pronounced for providers in rural areas. The rural providers reported matters related to stigma and discrimination were significant barriers to services, and that geographic differences and lack of transportation presented major challenges.

D. 2005 Statewide Coordinated Statement of Need

The 2005 SCSN was conducted by researchers from the University of Kentucky and centered on the findings from a series of focus groups held in each region of the State. Not surprisingly, findings focused on the implications of limited funding, but a suggestion emerged about the possibility of coordinated resource development as a function of the HIV/AIDS Branch.

Another important preference that emerged in this dialogue was a movement to service delivery models in which all relevant HIV services were available in one location. Consistent with this, participants advocated for increased cross-agency communication and collaboration. The challenges identified were fragmented services, lack of communication. The possibility of increased synergy through more regular collaboration was identified as a potential benefit.

An important clinical concern identified in this process was the increasing prevalence of non-HIV medical conditions, the burden of treating patients and challenges obtaining affordable medications for patients with these conditions. Another important concern raised was access to and utilization of oral health services. Participants also identified challenges in providing access to affordable dental health resources, especially outside urban areas.

E. 2007 Care & Prevention Needs Assessment

After consultations with the Health Resources and Services Administration (HRSA) and the Centers for Disease Control and Prevention (CDC), the state

Ryan White "Part B" grantee office participated in the 2007 Kentucky Statewide HIV/AIDS Needs Assessment which incorporated a single survey tool to assess statewide need regarding HIV/AIDS prevention and care services.

On the care side, issues from both the 2003 and 2005 Statewide Coordinated Statements of Need were heard again: increase funding to fill service gaps; increase staffing to handle growing caseloads; increase prescription coverage for co-morbidities; increase "one stop shop" sites where multiple services are coordinated centrally; introduce smoking cessation programs for positive clients; increase programmatic outreach to non-gay-identified MSM; and expand transportation and dental services.

The first prevention gap identified in this plan was one of accountability and tracking. Challenges included those posed by lack of HIV incidence data, challenges with agency's reporting practices, and subsequent difficulties in holding prevention grantees accountable for performance. The current enhancements in surveillance practices and monitoring tools are anticipated to address this challenge.

In terms of populations served, the lack of services and outreach to transgender clients was considered an important. The needs of non-injecting substance users were identified as a concern. Some respondents believed that these identified populations, especially high risk heterosexuals were not being adequately reached by existing prevention activities, even though the scope of the problem was clearly identified. Additionally, the dissolution of a number of community-based organizations providing prevention services focused on the needs of individuals who were racial and ethnic minorities were identified as creating a significant gap which would need to be addressed in order for prevention needs to be met.

Finally, a good deal of concern about access to and quality of HIV counseling and testing was noted. Recommendations were offered, including increased staffing for HIV counseling and testing sites, increased training for staff delivering the interventions, and advocacy for increased availability of rapid HIV tests.

The 2007 Care and Prevention Assessment was a joint collaboration between the HIV/AIDS Branch and the community planning group- Kentucky HIV/AIDS Planning and Advisory Committee (KHPAC).

F. 2008 Prevention Plan

The most recent prevention plan proposes public information campaigns as a way to increase public perception and encourage HIV testing. In addition, addressing the needs of underserved populations—particularly African-Americans and Hispanic clients—were recommended as priority activities. The unmet needs of injecting drug users and outreach to women and transgender clients were

identified. Finally, building the capacity of CBOs to address unmet needs was suggested.

A number of recommendations for enhancing testing and counseling were detailed. One relevant recommendation to enhance standardization of HIV counseling and testing was noted. Attempts to add additional testing personnel and venues were reported.

Finally, the successes at implementing Effective Behavioral Interventions [EBIs] were noted, but the need for enhancing the available options by identifying interventions targeting youth and women was also noted.

G. KY Department of Education Needs Assessment/Youth Risk Behavior Survey (YRBS)

The needs assessment demonstrated only a small percentage of statewide AIDS cases. However, the assessment also showed compelling identified needs for prevention activities for this population. Among the most significant implications is the disproportionate impact of AIDS on people of color, particularly African-American youth. This concern is corroborated by Youth Risk Behavior Survey (YRBS) data which shows increased incidence of sexual behavior associated with HIV risk among African-American youth.

Rates of HIV risk behavior appear to be highest among youth in urban Kentucky. The prevalence of surrogate marker of HIV risk—most notably unintended pregnancy and STD incidence—indicate the additional vulnerability of urban youth to HIV. A comparison of KY teen pregnancy rates and surrounding states suggest the challenge in KY is similar to the burden in nearby states. YRBS data indicates that use of alcohol and other drugs is a significant challenge in KY-especially related to prevalence of marijuana and alcohol use; in each case, KY ranks in the top 20% of states in national trends of use of these substances.

This report highlights the success of an 18-year intervention of school based HIV prevention activities. These courses, taught primarily by school teachers, reach some 600 Kentucky youth.

The KY YRBS data is part of a national process funded by CDC to determine needs of youth in a broad range of public health areas.

H. NASTAD African-American Needs Assessment

Like much of the Southeastern United States, the burden of disease in HIV among African-Americans is of great concern. Working collaboratively with the National Alliance of State and Territorial AIDS Directors (NASTAD), the branch used this assessment to look at unmet needs for prevention and care among

African-Americans in Kentucky. Like most of the Region, the impact of HIV on African-Americans is dramatic.

Results of consumer focus groups indicated high levels of satisfaction with care coordination, but identify a need for increased cultural competence from coordinators in some regions of the state. Clients reported high levels of satisfaction with clinical care received, but expressed concern about potential breaches of confidentiality in clinics. Perhaps the most compelling data gathered via focus groups involved issues of stigma and discrimination. Participants reported high levels of prejudice against individuals with HIV and report significant concern about need for confidentiality and the negative consequences of individuals being identified as living with HIV.

Care providers identified in separate focus groups the value of collaboration and effectiveness of interaction between medical and care coordination staff. Care providers saw utilizing media outlets and public information campaigns as important tools for addressing the impact of stigma and discrimination for African-Americans living with or at-risk for HIV. The recommendations included activities to change community norms while working on increasing capacity within CBOs and health departments.

VII. Summary of Identified Statewide Concerns

The 2009 SCSN has drawn primarily on the review of existing needs assessment materials. To augment the process, participants in the process (all subject matter experts) did include anecdotal material. It is believed this information based in practice experience enhances the findings of unmet need and makes this document and process more consistent with current trends and need in the provision of services to Kentuckians living with HIV/AIDS.

In the 2009 Kentucky Comprehensive Plan, goals and strategies have been developed to address many of the prioritized issues identified under this section. If feasible, the ultimate goal of the Branch is to eventually address all of the major issues incorporating the solution strategies proposed within this document.

Concerns, Gaps, Unmet Needs
1. Care Coordination
1.1. Transportation needs of clients--especially those in rural areas--are not seen as core services. This gap affects care provision and retention to care for patients living outside urban areas or without access to personal transportation. 1.2. Gaps in Federal support for housing needs (e.g. first month's rent or deposits) mean grantees must use resources to address these needs. 1.3. Care coordinators provide a vital link to primary medical and other core services, but are burdened with growing caseloads and have difficulty maintaining contact with clients as regularly as would be good practice. 1.4. Limited resources of the Kentucky AIDS Drug Assistance Program (KADAP) are

not keeping pace with increased demand.

1.5. Additional need for non-HIV medications creates further strain on drug assistance budgets.

1.6. A limited, loosely coordinated network of legal support for PLWHA exists. While there is one formalized program, the bulk of legal issues of PLWHA are addressed by an informal network of attorneys and legal experts.

1.7. Increasing challenges of clients with mental health problems. Difficulty exists in finding mental health providers who will see clients with limited financial resources, and the challenges of identifying funding for psychotropic medications are noted.

1.8. Many clients have existing substance abuse problems when enrolled in care, creating significant challenges. As with mental health clients, the complex challenges presented by these clients include resource constraints for treatment and medication, and resistance of substance abuse providers to provide care for clients who have limited resources for payment of services.

1.9. Systems of collaboration between local jails and Ryan White programs could be enhanced; HIV positive inmates are discharged with poor or no plan of follow-up for primary medical services or case management services. Need to enhance discharge planning and establish consistency when discharging patients from jails or prisons.

1.10. Severely limited housing for individuals with advanced HIV is concerning; and existing social service and homeless activities cannot adequately address this need. Many nursing homes and tertiary care facilities avoid providing services to individuals with HIV disease.

1.11. An unmet need for care coordinators exists in Part C clinics.

1.12. Patient medical information is often being discussed in non-private settings such as the waiting room and the front desk. Participants from rural communities also highlighted reluctance to disclose status, even in medical settings, due to the fact that confidentiality is a big concern for clients.

1.13. Patients with poor health literacy--the ability to comprehend and apply health information--create challenges for providers and care systems.

All HIV medical clinics need medical case managers who are specifically trained on the medical aspects of case management such as procurement of medication.

1, 14, Patients who "fall off the radar screen" with the KY Care Coordinator Program should NOT be prevented from reapplying for 6 months.

PRIORITY CHALLENGES

- Need to begin to develop a discharge planning program within the prison system.
- Need to enhance transportation for medical appointments and meetings with case managers.
- Need to improve access to medications and medication adherence.
- Need to increase opportunities for education, training, and professional development for Part B case managers on Medical Case Management.

- Need to address mental health and substance abuse needs of patients, particularly when specialty care is indicated.

2. Clinical Care

2.1 Access to medical care, as noted above, is challenging. Patients in rural areas often drive many hours to care sites. In addition, stigma and fear of discrimination make accessing care difficulty for clients in many parts of this largely rural state.
2.2 Significant geographical gaps in care exist; limited care providers especially in rural parts of the state pose concerns about the burden to care providers. Conversely, in the most urban regions, particularly the Louisville and Lexington areas, the number of patients in busy care settings creates a similar burden for different reasons.
2.3 Co-morbid conditions create many challenges for HIV care providers. Time and resources to manage issues like sexually transmitted infections (STI)s, hepatitis, and other chronic conditions are increasingly common and demand clinician's attention and resources.
2.4 Quality Improvement activities tax existing human and financial resources. Though QI measures for clinical care are in place, the requirement to hold meetings and document initiatives places a burden on care providers.
2.5 Challenges integrating prevention into care have been identified. With limited human and financial resources, the expectation of care providers providing prevention interventions at every clinical visit creates a burden.
2.6 Burden on care provision systems is growing. Expensive labs for resistance testing and new medications mean strain on both financial and human resources.
2.7 Adherence protocols are increasingly challenging as patients with mental health and substance abuse problems present for care.
2.8 Medical providers who do not treat HIV have limited HIV knowledge and limited expectations of receiving ongoing HIV education.
2.10 Pharmacies in rural areas do not have HIV drugs available.
2.11 Small clinics in rural areas do not receive Ryan White funds for self-pay patients. There is also a lack of psychiatric support available for individuals in rural areas.
2.13 Patients presenting with advanced disease cost more to treat and burden the system. Primary care provider must prioritize care for clients. HIV life expectancy now approximates the national average.
2.14 There is a need for providers to be close to clients' residence for acute and general care.
2.15 Unable to prescribe non-HIV medications or specialty referrals (ex. Chest X-rays, etc.)
2.16 There is a need to establish a sub-speciality medical support system available to all clients.
2.17 Non-HIV related medical assistance should be available to all clients. Funding for medical specialties should be reestablished for outpatient care.
2.18 Hepatitis C testing should be enhanced, with additional follow-up care.
2.19 There are limited home health care services available for individuals who lack

private health insurance.
2.20 There are individuals who could benefit from hospice care who are not eligible because they wish to keep taking ARVs.

PRIORITY CHALLENGES

- There is a strong need to increase access to care.
- The resources and availability of clinical care providers to manage co-morbid conditions and lack of sub-specialists who will treat HIV patients is concerning.
- There is a need to increase collaboration between prevention and care providers.
- There is a need to establish a comprehensive network of primary care providers for HIV positive patients, with close subspecialty support.

3. Collaborations

3.1 Need to increase collaboration with the Department of Corrections and local jails/ correctional settings. Communication about adherence and discharge planning needs will enhance continuity of care.
3.2. Statewide Care standards, especially with care coordination, need to be established.
3.3 Identified need for smoking cessation programs targeting individuals in HIV care; rates of tobacco use are higher in Kentucky than the national average.
3.4 STD treatment and care is available for many diseases, but screening for HPV and herpes is not available. Particularly, not being able to diagnose herpes has very significant implications for HIV care and prevention.
3.5 Administration of Part B and Part C clinics is fragmented, especially in light of the availability of care coordination at all sites.
3.6 A number of HIV care settings do not provide prevention services in their agencies.
3.7 Medicaid and Medicare provide some additional support for care of PLWHA. Still, the number of uninsured/underinsured patients and lack of providers who accept Medicare and Medicaid creates a significant gap in care for PLWHA.
3.8 Poor internal collaboration is noted between HIV and STD, Hepatitis [no public testing or treatment programs are available], TB, immunization, and Maternal and Child Health within the Department for Public Health.

PRIORITY CHALLENGES

- STD treatment and care is available for many diseases, but screening for HPV and herpes is not available. Particularly not being able to diagnose herpes has very significant implications for HIV care and prevention.
- Medicaid and Medicare provide the largest funding sources highlighting a pertinent need for ongoing collaborations to ensure that the services being provided are responsive to the needs of PLWHA. There are too many

uninsured/underinsured patients and too few providers who accept Medicare and Medicaid.
- There is a need for improved internal collaborations between the HIV, STD, Hepatitis, TB, immunization, and Maternal and Child Health programs within the Department for Public Health.

4. Dental/Oral Health

4.1 Chart review indicates more than 90% of patients have unmet dental needs. These included fillings, crowns, bridges, extractions, and oral lesion diagnosis.
4.2 Kentuckians—including those with HIV—have a higher than average rate of natural teeth extraction.
4.3 Individuals at lower socio-economic levels are less likely to visit the dentist than individuals with more resources.
4.4 Kentuckians have significantly higher rates of tobacco use and the concomitant challenge of increased risk for periodontal disease.
4.5 An uneven distribution of dentists in Kentucky creates problems of access-most notably in Eastern Kentucky.
4.6 While both University of Louisville and University of Kentucky have dental schools that provide care to indigent patients, limitations on the number of patients that can be seen and challenges of finding transportation can involve overcoming distances of two to five hours' drive.
4.7 Barriers cited in receiving oral health care included discrimination, affordability, fear of disclosing HIV status to dental care provider, lack of insurance, and lack of accessible providers.
4.8 Dental education/counceling to dentist to encourage providing care to HIV positive patients.

PRIORITY CHALLENGES

- Lack of enough slots for clients in the University of Louisville Part F program (Oral Health).
- Some Dentists lack HIV information and education.
- Clinical care providers often lack knowledge of oral health issues.
- Dental patients are lost to follow up.
- Transportation is sometimes a challenge, especially in rural areas.

5. Disenfranchised Populations

5.1 Providing effective translation for Spanish-speaking clients is challenging. In addition, an increasing number of immigrants who present linguistic and cultural challenges to care service delivery are being identified as disenfranchised.
5.2 Increasing HIV rates among heterosexuals, particularly African-Americans, is

concerning.
5.3 Lower-income and less-educated PLWHA who enter care, are diagnosed later in the disease process (e.g. entering care following an oportunistic infection/OI diagnosis), and often present adherence and compliance challenges to the treatment system.
5.4 Limited resources for traditional 'outreach' activities targeting this group may be creating gaps in diagnosis and difficulty accessing care for socially disenfranchised Kentuckians.
5.5 One in five MSM consumers do not identify as 'Gay'; need exists for culturally-sensitive care and prevention interventions to address the needs of these men.
5.6 The needs of pregnant women were identified as being a significant concern; linkages between obstetricians and HIV care providers are identified as needing improvement.
5.7 Reaching the needs of Kentuckians who are incarcerated is a challenge and has been identified in multiple resources as being a significant unmet need which calls for improved collaboration with correctional systems.
5.8. The needs of transgender individuals, although difficult to document in surveillance figures, has been noted as a concern. Bias against these individuals, as well as a documented history of risk behavior, offers concern for both prevention and access to HIV care.
5.9 Immigrants and other disenfranchised individuals coming into complex and organized systems of care may lack skills and experience to negotiate these systems.
5.10 There is a need to build a statewide network of African Americans who would advocate for PLWHA, and address issues of racial separation, apathy, distrust of community and public health systems, and the health seeking behaviors of African Americans

PRIORITY POPULATIONS

- Spanish speakers
- African-Americans
- PLWHAs (Especially those who were Diagnosed late)
- Non-Gay identifying MSM
- Pregnant women
- Incarcerated clients
- Transgendered persons
- Immigrants
- Rural clients
- Poly-substance users
- Truckers
- Sex workers
- Runaway youth
- Refugees

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6. Prevention

6.1 Transportation costs for testing and outreach staff are increasing.
6.2 Many at risk persons are meeting on internet sites and chat rooms; existing prevention interventions have not been adapted to meet this need.
6.3 Need for enhanced training of test counselors, especially regarding counseling needs of persons who test positive.
6.4 Measuring effectiveness of Evidence-Based Interventions (EBIs) is challenging. In terms of implementation of EBIs in KY, the difficulty to do impact or outcome evaluations make it unclear about whether these interventions have efficacy for prevention in KY.
6.5 Need to increase the involvement of faith-based organizations to provide comprehensive prevention efforts.
6.6 Lack of information about HIV risk for non-injecting substance users identified as a problem; increased use of methamphetamine in particular poses new challenges.
6.7 Gaps in access to HIV prevention for rural Kentuckians are an ongoing problem. There are insufficient HIV testing and counseling services in many regions.
6.8 Unmet needs of transgender Kentuckians are a concern. Though the actual number of transgender clients living with HIV remains relatively low, the absence of identified effective interventions targeting this population and national trends documenting high prevalence rates in this population are concerning.
6.9 Kentucky and national data suggests individuals with HIV who know their status are more likely to use barrier protection during sex. The need to increase the number of Kentuckians with HIV who know their status should be a priority.
6.10 STD data suggests significant syphilis/HIV co-infection in 2007; this reinforces the need for ongoing HIV/STD prevention interventions with PLWHA.
6.11 While effective collaborations exist between care and prevention staff in many regions, opportunities for enhanced collaborations and cross-training have been identified.
6.12 There is a need for additional EBIs to reach additional populations or provide support for adaptation of existing interventions.
6.13 Limited resources available for community-based organizations makes community capacity-building challenging and may impede effectiveness of prevention efforts. A concurrent theme of limited staff to implement prevention activities is also noted.
6.14 Requirement of pre-test counseling can create a burden for health care workers in busy settings or settings where HIV tests should be performed.
6. 15 Gaps in educational materials provided to youth that meet all the needs of youth and not just abstinence only programs. Education in high schools is inconsistent and inadequate.
6.16 Need for HIV education and prevention for inmates in KY correctional settings
6.17 Many Kentuckians-especially in rural areas-lack information and access to HIV testing and counseling. Need for HIV testing on admission to KY Correctional facilities to initiate treatment and provide prevention interventions.

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PRIORITY CHALLENGES

- There is need to address the costs associated with medical transportation.
- There is a need for enhanced collaborations with Faith-based organizations.
- Outreach and prevention activities in rural areas are difficult to accomplish.
- Addressing the needs of transgender clients is challenging.
- There is a need for individuals to know their status.
- There is a need to increase efforts to achieve the requirement of pre-test counseling.
- There is a need for HIV education in schools.

VIII. Proposed Strategies to Address Concerns

Concerns, Gaps, Unmet Needs
1. Care Coordination

- Seek additional funding for transportation
- Increase funding to hire additional care coordinators, improve staffing levels, and provide prescription coverage for co-morbidities.
- Additional, housing funds should be made available to pay outstanding utility bills so that current utilities can be turned on.
- Develop model for "one stop shop" facilities.
- Expand transportation and clothing services.
- Develop ambulatory/outpatient care to include transportation, buddy system/ride sharing, and volunteer services (churches, buses, taxis)
- Use CBOs and resources from Part B award and work with clients to develop payment plans and budgets; educate clients about energy conservation.
- Hire more case managers by shifting resources from services to staff; this should follow the mandate to move to medical case management (MCM).
- Use Patient Assistant Programs (PAPs), preauthorization, caps on meds, tax rebate monies, and client co-pays to address the cost of prescription drugs.
- Collaborate with other CBOs to purchase non-HIV meds utilizing local pharmacy pricing.
- Collaborate with local legal offices and law schools to solicit help with legal protection and advocacy per FY '08 grant.
- Collaborate with comprehensive care and local mental health care to provide training on addressing the needs of severely mentally ill persons.
- Collaborate with substance abuse programs to provide outreach to substance abuse facilities that don't specialize in STD/HIV.
- Educate Part B providers on correctional systems; develop discharge planning process in prisons. Provide education in local jails regarding comprehensive care.

- Provide education in nursing homes regarding HIV care.
- Collaborate with home health and palliative care organizations.
- Provide training on confidentiality and patient health information; assure that confidentiality forms emphasize accountability for breeches of confidence.
- Continue providing education to case managers/medical case managers on HIV basics, prescriptions, and adherence.
- Expand presence of case management into all Part C clinics.
- Expand use of electronic medical records to increase portability and communication in patient medical records.

2. Clinical Care

- An education campaign for primary and Family Healthcare Providers and emergency rooms.
- State wide advocacy for HIV education of medical providers to return to a bi-annual system instead of every 10 years. This should include all disciplines, including mental health, and substance abuse providers.
- Implement a Department of Corrections (DOC) policy on lab schedule for HIV+ inmates similar to the policy in the free world clinics-every 3 months.
- Develop strategies to advocate for coordinated clinical care in county jails.
- HIV+ inmates should be seen at least quarterly to review lab results and make sure no other problems are occurring.
- All newly diagnosed HIV+ inmates should be referred to an Infectious Disease physician.
- DOC should change discharge policy to include:

    a. Meet with inmate and review disease process.
    b. Inmate sign Release of Medical Information form so medical records can be sent to HIV clinic or medical person inmate requests. If inmate refuses, then he gets copies of lab and any other HIV related records.
    c. Discharge nurse will call HIV Clinic and speak to Care Coordinator to arrange appointment date. Inmate can also speak to Care Coordinator if he or she has questions.
- Develop standards of care in all Part B programs which are integrated into Part C settings.
- Use Part B funds to employ two new specific care coordinators: one to deal with new immigrants and one to deal with corrections issues.
- Make HIV drugs available in rural area pharmacies.
- Seek Ryan White Grant Fund for HIV treatment in small clinics.
- Provide Psychiatry/Psychology hotline for referrals.
- Train internists in rural areas to provide services for HIV primary care problems to reduce travel to care sites. Establish processes and communication to train, support, and provide technical assistance to medical staff in order to accomplish

this initiative.
- Consider creating medical school programs—especially in internal medicine and family medicine—to encourage engagement in HIV care.
- Partner with Community Health Centers to increase their capacity to provide primary care and have HIV providers offer testing and prevention services in CHCs.
- Consider reducing lab costs by negotiating statewide contracts with agencies.
- Enhance education and training for all health care workers. Lobby for mandatory HIV training more often, network with the Branch and Part F AIDS Training and Education Center for policy change.
- Establish a clinical care facility that can fill currently lacking services in Eastern Kentucky.
- Provide smoking cessation programs at all Part B, D, and F facilities.
- Facilitate linkage between Part B programs, Disease Intervention Specialists (DIS), and prevention programs to ensure provisions of evidence-based prevention services to PLWHAs.
- Enhance collaborations at state and local levels to increase STD and Hepatitis testing and care.
- Enhance collaborations with primary care providers by offering testing and prevention services and asking for help managing complex patients with non-HIV illnesses.
- Consider renting vans to transport multiple rural patients to appointments.

3. Collaborations

- Provide Quality Improvement workshops at the State Conference and spread the word about TA availability.
- Collaboration with the DPH, HIV/AIDS Branch on training and engaging the Prevention Specialist and Care Coordinators in providing education and develop continuum of care. Identify and tie together the mission and goals of the Department of Corrections and the Kentucky Department for Public Health.
- Develop a pilot project that integrates Public Health Services within the Kentucky Department of Corrections.
- Foster collaborative linkages between the State and the community to offer cross trainings on interagency programs and State agency policies in order to support and sustain new initiatives.
- Capacity Building needs to be encouraged and funded to non-governmental contracted CBO's for geographically underserved areas of the state.
- Integrate HOPWA staff into Part B and Part C clinics so patients in need of housing will have access.
- DPH, Medicaid, and Medicare should create a joint task force to facilitate information exchange. This task force will identify joint initiatives such as data

exchange, cross check patients who are eligible, and transition them to Medicaid/ Medicare. This will also allow for cross-program input on HIV related policies.
- Look at ways to expand providers who recognize/accept Medicaid/Medicare. Identify states that have had success in expanding network of Medicaid/Medicare providers and collaborate to implement steps they took.
- Program managers for HIV, Communicable Diseases, Adult and Child Health should designate a staff member from each program to an internal DPH committee that wiould be charged with identifying opportunities for joint projects (e.g. implementing routine HIV testing and prevention services for adults, pregnant women, and infants in regions with high HIV/TB/STD/Hepatitis prevalence).

4. Dental/Oral Health

- Expand dental services.
- Provide case workers in dental settings to assist in finding patients lost to follow up or who need transportation.
- Provide training to dental providers on basic HIV, oral health manifestations, and routine oral health care for PLWHAs.
- Clinical care providers should receive training on dental screening.
- Expand on use of mobile dental unit to expand services and increase dental slots.
- Continue to enhance multi-disciplinary collaboration.

5. Disenfranchised Populations

- More individuals from disenfranchised groups engaged in advocacy work on state and federal levels might be helpful.
- Develop standards of care for translators and mandating HIV 101 be taken by the translators.
- There is a need to build a statewide network of Black advocates for PLWHA who will, among other things, look into issues of racism and its impacts on health-seeking behaviors of African Americans, community distrust, and lack of response from the public health system.
- Work with colleges and universities, Catholic churches and other agencies.
- Increase sub cultural sensitivity.
- Create collaborations with agencies with specific service focus, i.e. incarcerated populations, substance abuse, HIV prevention, intersecting missions.
- Expand the understanding and acceptance of definition of family and relationships as applicable to the various disenfranchised groups.
- HIV testing among pregnant women.
- Approach the trucking industry with help for their ‘bottom line’ for health care expense.
- Push the Kentucky Legislature for testing inmates in correctional settings and before discharge.

- Place HIV prevention and testing information in rest areas, truck stops, smoke shops to target truckers and substance users.

6. Prevention

- A statewide information campaign should be initiated…billboards, TV. and radio, etc
- Explore other funding opportunities and consider redrawing the Prevention regions
- Press releases should be done four to five times a year highlighting prevention activities. The DPH has established a link on the DPH website to add prevention and Counseling and Testing Services information.
- All Health Departments have access to the state training calendar (www.KY.TRAIN.org). The counseling and testing training has been approved by TRAIN for continuing education credits (CEUs).
- Counselors' training should be modified so that counselors receive training on HIV CTRPN goals, prevention and behavior change counseling including the discussion of risk factors and development of risk-reduction plans, discussion of homosexuality and more specifics of risk behaviors, and how to counsel an HIV positive client.
- New generations of GLBT populations need to be informed on HIV issues; continued education remains a priority
- More fully engaging HIV-positive individuals in prevention activity is an important possible enhancement.
- Continue efforts to partner with African-American churches and seek to develop relationships in additional denominations. Develop list of churches willing to address HIV issues, and establish relationships to foster service delivery.
- Schedule multiple activities in the same trip. Coordinate travel between agencies in the same region. Use agency vehicles.
- Ask host agencies to provide transportation.
- Collaborate with rural service providers.
- Use media outlets in rural areas to raise awareness.
- Work with service providers to market prevention services including testing events.
- Provide specialized services for transgender clients in STD clinics, and focus on transgender programs by building on MSM and IDU programs.
- Request for technical assistance from CDC to address identified contractor needs.
- Train additional staff in facilities to do HIV pre-test counseling.
- Examine clinic flow to see when counseling can be performed.
- Facilitate campaigns that focus on personal risk.
- Collaborate with the community planning group and the advocacy group to advocate for comprehensive sexuality education.
- Work with the Kentucky Department of Education.

- Promote efforts to reduce the stigma of being HIV-positive.

IX. Challenges to Care Access

Current Efforts to Find People Not in Care

The 2009 Comprehensive Plan utilized information from the SCSN that was identified by various HIV/AIDS stakeholders across the state via the documents listed in Section II, as well as information from the unmet need framework. Many of the same barriers and gaps to care were identified in all the documents. Long and short term goals were developed to strive to assist Kentucky's Part B program to identify and provide care linkage to people who are HIV infected, but not in care. For example, Transportation continues to be a barrier to care. Therefore, Kentucky has identified a short term goal of implementing vanpools in all of the six direct service regions in order to address the lack of transportation resources.

Oral health for HIV infected individuals is critical to the overall health of the infected person. The SCSN determined that many dentists across the state need training on the linkage between oral health and HIV. The Kentucky HIV/AIDS Branch will conduct four (4) HIV 101 trainings to dentists in the rural areas of the state in order to assist dentists with identifying patients who are infected with HIV and direct them to seek medical care. Medication adherence is a vital link to the HIV infected individual's healthcare. The Kentucky AIDS Drug Assistance Program (KADAP) will work in conjunction with adherence specialists, medical providers and the six (6) direct services supervisors to train Care Coordinators on medication adherence so that they can effectively identify and provide guidance to non adhering clients.

The SCSN identified the need to collaborate with the Kentucky Department of Corrections to provide HIV testing, education and discharge planning to inmates in order to identify and retain inmates in care. Kentucky will begin the first phase of implementing a HIV Discharge Planning, HIV education and testing at LaGrange Correctional facility (which holds the largest number of HIV+ inmates) beginning January, 2009.

The majority of HIV/AIDS cases (both in and out of care) in Kentucky are among the Men who have Sex with Men (MSM) population. To provide effective prevention case management to HIV+ MSMs, collaborations between the HIV prevention and the Part B and C programs will be conducted to facilitate prevention efforts to individuals seeking HIV related treatment. This will allow the prevention staff to identify and provide care linkage to partners of infected MSM who may be HIV infected, but not in care.

According to the unmet need framework, a greater percentage of HIV+ Blacks and Hispanics had an Unmet Need (36% and 6% respectively) in comparison to those with Met Need (at 32% and 3.4% respectively. Additionally, the 2000 U.S Census Bureau report, the total population in Kentucky as of July 1, 2007 was 4,241,474 with 8% self

reporting as Black (non Hispanic) and 2% as Hispanic. While Black (non Hispanics) and Hispanics represent small proportions of Kentucky's overall population, they represented 32% and 5% respectfully, of the persons living with AIDS as of December 31, 2007, and 50% and 10% of the new AIDS cases diagnosed between January 1, 2006 and December 31, 2007. Kentucky continues to see a population increase of Hispanics as they travel to Kentucky for work on horse farms and in tobacco fields. Due to the increase in the Hispanic population, Kentucky has also seen an increase of HIV infected Hispanics. The Part B grantee staff will conduct an assessment to identify areas which have the highest and fastest growing populations of Hispanic individuals and will contact Community Based Organizations (CBO's) and social service agencies serving these populations to provide HIV education, testing and linkages to care for HIV infected Hispanics. Collaborations with Hispanic specific agencies will enhance communication efforts and allow for better provision of care and supportive services.

The largest minority population in Kentucky is the African American population. African Americans make up 31% of the total AIDS cases but only 8% of the general population, therefore, seeking those individuals who are HIV infected, but not in care is vital to healthcare. Part B staff will collaborate with churches and various organizations within the African American community to provide HIV 101 trainings, testing and enhanced linkage to care services. This will provide cultural competency training, reduce stigma within indigenous African American churches, educate the African American community on the prevention and spread of HIV/AIDS, as well as identify HIV+ African Americans and link them to care.

Mental health and substance abuse issues plague Kentuckians, particularly those in rural regions. Those individuals who are infected with HIV and also have mental health or substance abuse issues are more at risk of not participating in HIV care and services. Many of the mental health and substance abuse centers lack knowledge about HIV. The 2009 Comprehensive Plan will address this need. The Part B grantee office will conduct an assessment to determine what areas of the state have the highest prevalence of mental health and substance abuse issues and contact service centers within these regions to provide staff with HIV "101" classess and provision of counseling, testing and linkage to care services.

The 2009 Comprehensive Plan will include an initiative to address the HIV needs of homeless populations. Therefore, the Part B staff will collaborate with the major homeless shelters in Louisville and Lexington (the regions with the highest prevalence of HIV and homeless) to begin an assessment of the HIV needs within the homeless population. The collaborative goal is to increase staff HIV knowledge, improve/establish testing programs and linkage to care. This will identify HIV unmet needs of major homeless shelters in Louisville and Lexington and assist in retention in care.

The Kentucky Part B program goals and objectives center around retention in care for those HIV infected individuals who are in care and those who are out of care. In

Kentucky, three KHCCP contractors receive both Part B and Part C funding. In addition, the contractor for the Louisville region houses a Part B staff person at the WINGS Clinic. Collectively, these particular contractors serve the majority of KHCCP clients. Through these collaborations, clients who may have fallen out of care or are at risk of being lost to follow-up are more easily monitored and targeted for retention in care efforts. In Kentucky, the Part C (treatment) and Part B (direct care and support services) program staffs share many of the same clients and communicate frequently to coordinate needs of consumers.

Findings Regarding Disenfranchised Populations:

The disenfranchised populations identified in the SCSN process underscore the connection between HIV and social inequality and the concomitant issues that affect all disenfranchised populations. Among the unique needs identified in these populations are issues of HIV related stigma. In many areas and in multiple populations, the prejudice and discrimination of living with HIV is a huge barrier to engaging individuals in HIV care. In rural areas, the idea of being seen attending an HIV care clinic presents a major barrier for individuals living with HIV.

In addition, the stigma associated with risk behaviors linked to HIV is another aspect of the fear that impedes individuals from accessing both prevention and care services. As a majority of Kentuckians affected by HIV contracted the virus through MSM activity, the impact of homophobia on care-seeking and treatment compliance is noted. Moreover, for many patients affected by HIV, the issue of discomfort around sexuality presents additional obstacles. Issues of infidelity, sexuality, and sex outside the context of marriage have substantial cultural stigma; and the shame associated with these risk behaviors is a barrier to care.

The impact of racism and historical oppression must be factored into an understanding of the challenges facing those attempting to provide care to PLWHA who are racial and ethnic minorities. Clearly, national studies show poorer access to care and poorer health outcomes for those who are socially-disenfranchised because of race; this is striking even in Kentucky which has a relatively small non-White population. The linguistic and cultural issues of Hispanic Kentuckians and new, non-Hispanic immigrants to Kentucky are substantial challenges for the health care delivery system.

Finally, the issue of health literacy and the ability of the affected individual to participate in care, has become an increasing barrier and a burden to the health sector. As the population of individuals living with HIV continues to change, the needs of individuals whose cultural and linguistic histories make participation in health care system challenging must be addressed. New models of recruitment and retention will have to be adapted to address these growing challenges.

Strategies to Increase Access to Care for Disenfranchised Populations

Disenfranchised populations have a wide array of social/economic barriers and impediments to information about HIV/AIDS and prevention and care resources. The 2009 SCSN identified several promising approaches to addressing needs in this area. First among these are cultural competence efforts which seek to create a welcoming climate for disenfranchised populations. Beyond training on the provider level, effective multicultural organizations address how systems and processes can become more culturally competent to serve the needs of unmet individuals.

Second, efforts to reach vulnerable populations must engage communities at the onset to create ownership in the process and to identify gatekeepers whose presence and support can be critical for public health interventions to succeed. Every effort must be made to make programs participatory, engaging community partners at every phase in the process.

Next, new efforts to find locations where marginalized populations are found must be identified. Having easily accessible outreach and case management staff, brochures and health marketing material is a critical aspect of bridging the gap between individuals not in care and the care system.

Finally, the success of identifying individuals living with HIV and not in care is intricately connected to counseling and testing efforts. In line with the CDC's Advancing HIV Prevention Initiatives and the 2006 Recommendations for Routine HIV Screening in Medical Settings, the HIV/AIDS Branch is committed to finding those Kentuckians living with HIV who do not yet know their status. The 2009 comprehensive plan goals of the Branch include finding those individuals who do not know they are infected, counseling their partners, and assisting them in accessing available care services.

IX. Summary and Conclusion

The 2009 Statewide Coordinated Statement of Need offers an important view into the challenges and opportunities facing all providers in Kentucky who wish to address the unmet needs of PLWHA. There are, indeed, many problems which persist from previous assessments: issues of stigma, limited resources, challenges of multiply-diagnosed consumers, and the geography of Kentucky are themes which repeated themselves in this assessment. On the other hand, successful prevention efforts and innovative models of recruiting and retaining consumers in care offer hope in moving forward. Many resources exist for individuals living with HIV/AIDS, and effective coordination of these resources and creative strategies to address unmet needs offer hope for the future of the HIV/AIDS response in Kentucky.

As with other health issues, the assessment of unmet need is intricately linked to the reality of other health disparities. Like other chronic conditions, the disproportionate impact of HIV on racial and ethnic minorities must remain a primary concern. In addition, issues of class and gender and the impact of homophobia are all larger social issues which impact the lives of Kentuckians affected by HIV. With careful consideration and with focused persistence, impact on these issues can be made via implementation of the 2009 Comprehensive Plan.

Perhaps most importantly, the SCSN was a rich and successful process for the HIV/AIDS Branch and the statewide network of partners whose efforts have borne fruit in this document. The willingness of HIV providers to find time in their busy schedules to make time was significant; their thoughtful attention to the detail of this process was inspiring. Clearly, there are significant challenges, but the skills of these individuals, the determination of individuals living with HIV/AIDS, and the resource of the HIV/AIDS Branch will be channeled to address the unmet needs of Kentuckians living with HIV/AIDS.